

# *Components of a Comprehensive Care Model for Dementia*

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#DementiaCareSummit

## Care Model & Basic Features

### ***Clients***

- Both Person with Dementia (Person), and primary family or friend Caregiver(s) (if present)
- Other family and friends, determined by Person and Caregiver

### ***Consumer Directed***

- Person and Caregiver lead
- Other family members and friends, as determined by Person and Caregiver
- Professionals provide care, services, coaching, and support

### ***Duration***

- Long-term, through all phases of disease history
- Through all care transitions and changes

### ***Coordinates Support, Care, Services, and Other Resources***

- Gives information, facilitates use, monitors, helps with changes



## Care Model & Family-Friend Network

- Mobilizes and coordinates involvement by family, friends, neighbors, etc.
- Continuous monitoring and adjusting network involvement
- Builds consensus among network members
- Facilitates communication among network members; Helps keep everyone informed in accord with preferences of Person and Caregiver



## Care Model & Medical/Community Services & Care

### ***Medical Care***

- Facilitates primary medical care as an ongoing partner; Offers guidance on effective use and communication
- Facilitates use of specialty medical care and therapies
- Monitors medications and care for co-existing conditions

### ***Community Services and Programs***

- Provides information about and facilitates use of all community services/programs (e.g., home health, personal care, chore services, adult day, case management), and evidence-based dementia caregiving programs
- Monitors quality; assists with starting and/or stopping



## Care Model & Support-Information Resources

- For the Person and Caregiver, if present
- Provides information about and facilitates use of print and online resources, evidence-based programs, and other programs/services
- Links to and facilitates use of programs/services of the Alzheimer's Association, other Dementia-Specific Organizations, Area Agencies, Respite Programs, etc.
- Provides information and facilitates use of dementia-friendly businesses, attorneys, transportation, assisted livings, nursing homes
- Coordinates and tracks use of all resources



## Care Model & Identification of Problems/Concerns

- Ongoing assessment and reassessment; Not just at enrollment or after 6- or 12-months
- Equal attention to Person and Caregiver
- Holistic – address broad range of potential medical and non-medical problems/concerns (e.g., benefits, finances, symptom management, family communication, pain, stress, planning, anxiety)
- Guided by priorities of the Person and Caregiver
- Safety net, so important issues are not overlooked





## Care Model & Action Plan or Care Plan

- Behavioral Action Steps (including use of programs, services, and information) that move toward solutions to problems important to Person and/or Caregiver
- Action Steps by Person, Caregiver, Family/Friend Network, and Professionals
- Continuously evolving, as symptoms, caregiving, and preferences change
- Guided by preferences of the Person and Caregiver, with coaching and guidance by professionals
- Address immediate problems and prevention/planning



## Care Model & Areas of Assistance

Get/Understand Diagnosis & Prognosis	Support Coping with Illness & Caregiving
Manage/Understand/Monitor Symptoms	Transition Locations for Care
Get Primary & Specialty Medical Care	Coordinate/Communicate with Family/Friend Network
Learn Dementia Communication Skills	Maintain Health, Wellness, Pleasant Activities
Get/Monitor Daily Tasks (e.g., Driving, Personal, Household)	Assist with Legal-, Financial- & Care-Planning
Assist with Finances (e.g., insurances, benefits, bills, accounts)	Support Relationship of Person & Caregiver
Access/Coordinate/Monitor Medical Care, Therapies, Community Services, Support-Information-Other Resources	Ongoing Identification of Problems/Concerns
Learn Care and Caregiving Skills	End-of-Life Planning & Care



## Care Model Feasibility

No one comprehensive model exists; Can be created by combining:

- Multiple and complementary evidence-based dementia caregiving programs
- Existing community services, support-information programs, and resources
- Primary medical care
- Facility-based locations for care
- Ongoing care coordination and coaching
- Individualized assistance based on preferences, stage of disease, co-existing conditions, living arrangement, etc.



## Recommendations for NIA, ACL, PCORI & Foundations

Support pragmatic trials, translational research, and comparative effectiveness studies testing the effectiveness, feasibility, and acceptability of comprehensive care models with the following components:

- Directed by and give equal attention to the Person and Caregiver
- Provide continuous assistance and support from diagnosis thru the end-of-life, with ongoing adjustments to changes in the illness and/or caregiving
- Holistic in the types of medical and non-medical issues addressed, in accordance with the preferences of the Person, Caregiver, and selected family members and friends.
- Coordinate and facilitate access to assistance and support from: a) family members, friends, neighbors; b) primary and specialty medical care and therapies; c) support-information-education programs/ services; and d) dementia capable community resources.
- Combine complementary evidence-based programs with existing programs and services from established community organizations and resources.

